

8-30-2003

## Resist Newsletter, Aug. 2003

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### Recommended Citation

Resist, "Resist Newsletter, Aug. 2003" (2003). *Resist Newsletters*. 354.  
<https://digitalrepository.trincoll.edu/resistnewsletter/354>

*Funding social change since 1967*

# RESIST

ISSN 0897-2613 • Vol. 12 #6

*A Call to Resist Illegitimate Authority*

August 2003

## HIV/AIDS Resistance

### *AIDS Activism from ACT UP to Today*

JULIE DAVIDS

The radical AIDS movement was born in anger, and there is still plenty to be angry about. As we commemorate the 20<sup>th</sup> anniversary of the Denver Principles (<http://www.actupny.org/documents/Denver.html>), an unprecedented document demanding the rights of people with HIV, it is useful to look at the history of the movement, its transformations into present day efforts, and to consider future directions for sustaining and expanding its victories.

A group of people gathered in Denver in 1983, a scant two years after the first reports of cases of AIDS in Los Angeles, and two years before the HIV virus was identified. Their document of principles still forms the backbone of the ethics of self-determination of the AIDS movement. It begins, "We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS.'"

Thus, in the face of debilitating illness and death, near panic and widespread discrimination against those perceived to be infected, there was resistance to the dehumanization of people with AIDS. A burgeoning activist movement demanded a voice and issued recommendations that their peers "form caucuses to choose their own representatives to deal with the me-

dia, to choose their own agenda and to plan their own strategies... to be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations."

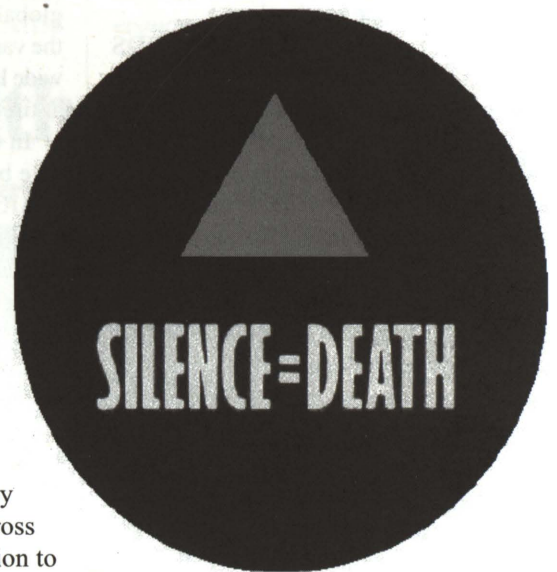
#### **ACT UP and Radical Resistance**

Four years after the Denver Principles, ACT UP New York burst into existence, quickly followed by over 100 independent chapters across the country. ACT UP (AIDS Coalition to Unleash Power) was vibrant, creative, fierce and successful.

But it is a real stretch to call the so-called heyday of AIDS activism in the United States the "good old days." They were, as one series of ACT UP New York protests labeled it, days of desperation.

People forged an AIDS movement as a community-in-struggle. Their community was united in caring for one another, literally providing the nourishment for those in the hospital when the nursing staff dropped their food trays at the door and fled. They took to the streets together, as people who felt they had nothing to lose, and because, in the words of ACT UP New York member Vito Russo, they gave a shit. At a demonstration at the US Department of Health and Human Services in 1988, he said:

*Why are we here together today? We're here because it is happening to us, and we do give a shit. And if there were more of us AIDS wouldn't be what it is at this*



*moment in history. It's more than just a disease, which ignorant people have turned into an excuse to exercise the bigotry they have always felt.*

*It is more than a horror story, exploited by the tabloids. AIDS is really a test of us, as a people. When future generations ask what we did in this crisis, we're going to have to tell them that we were out here today. And we have to leave the legacy to those generations of people who will come after us.*

Activists confronted AIDS-phobia, bias and neglect in the press, the public, the Reagan and first Bush Administrations, and in the private sector. They demanded a shift in medical research priorities – from arcane "bench research" to the development of therapies to save the lives—and the process of drug approval. These efforts se-

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cured government resources for HIV/AIDS prevention, treatment and care, and better policies concerning some aspects of the epidemic. Activists in and across communities of color demanded a voice within AIDS activist configurations, and formed alliances to demand services in local and community-led organizations.

After targeting by AIDS activists who interrupted dozens of campaign visits, Bill Clinton made significant promises to fight AIDS. His election in 1992 represented a watershed moment for many AIDS activists. The groundswell of AIDS activism began to subside.

## From Movement to Institutions

Ironically, the success of the AIDS movement had a demobilizing effect. To put it oversimplistically, people fought for treatment and services, for the right to be visible, and to be protected from discrimination. To a greater extent than some thought possible, they won. Though far from perfect or complete, services and treatments were put in place, and street activists could no longer argue that "nothing" was being done for people living with HIV. The provision of new funds for prevention and care services also meant that someone had to run them, and many surviving activists shifted to providing social services

In some cities, ACT UP chapters literally died off over the next few years; others chose to step away to reclaim lives put on hold in the pace of "crisis" activism. The increasingly mainstream and middle-class gay and lesbian movement, which began to prioritize "equal" rights to the military and marriage, distanced itself from pernicious AIDS issues like needle exchange or the ban on the immigration of people with HIV.

By the time more effective treatment hit the market in 1996, few AIDS organizations engaged in explicit community mobilization or organizing. In addition, at the local level, some leaders and organizers in struggling urban communities resented the seeming "exceptionalism" of HIV/AIDS specific programs while they continued to face multiple challenges of poverty, racism, incarceration, homelessness and other issues.

In the late 1990s, the burgeoning anti-corporate globalization movement, the ease of communication around the world through the internet, and the persistence of com-

munity organizing in some sectors of the US AIDS movement worked synergistically to re-infuse AIDS activism with a sense of purpose and connection in the struggle for global access to HIV/AIDS medication. The Health GAP Coalition continues the AIDS movement tradition of busting open the doors to the corridors of power, holding hard-line negotiations with the United States Trade Representative and WTO officials while sustaining direct action and supporting global days of protest for access to essential medications. (See article on page 6.)

## HIV/AIDS Activism Today

Yet, all is certainly not well now. The global epidemic continues unabated, and the vast majority of people with HIV worldwide lack access to basic medicine, let alone antiretroviral therapies.

In the United States, there are hard-to-take but often effective treatments, a web of AIDS-related services providing at least a partial safety net for many people living with HIV, and social sanctions against those who show outright anti-AIDS bias. Nonetheless, tens of thousands of people who fit the medical criteria for antiretroviral therapies are denied access to these treatments as funding for the federal AIDS Drug Assistance Program has not kept pace with the need.

Even with the strength of this global solidarity movement, AIDS-related organizing on domestic issues has subsided. The ultra-conservative and reactionary priorities of the second Bush Administration have started to dismantle the minimal safety net of HIV prevention, treatment and care.

The federal government has subverted the commitment to self-determination of the AIDS movement, promoting a web of "consumer" advisory committees, boards and commissions that have fostered an HIV/AIDS community leadership structure that is individualistic, isolating, non-strategic, competitive rather than collaborative, and often solely focused on the appropriation and allocation of federal funding.

Low-income people, people of color and immigrants bear the brunt of domestic policies dismantling vital social services, health care and civil liberties. These communities also face high rates of HIV, a lack of resources to combat HIV/AIDS stigma and homophobia, and barriers to health care and other services.

Despite the conclusive evidence that syringe exchange programs prevent the transmission of HIV without increasing drug use, there is still a complete ban on using federal funding for this proven strategy. And HIV has continued to track along lines of discrimination and bias in this country; as many as one in 50 African American men are believed to be infected, while a study of young gay men in six cities saw rates approaching one in three.

## So Now What?

To honor the rich legacy of the radical AIDS movement, we need to organize in a new context. We need to combat distance and historical suspicion between the AIDS movement and other movements for economic and social justice.

Some community leaders and organizers feel that AIDS gets enough attention and money already, while AIDS activists have sometimes underestimated the importance of ongoing struggles in communities that predated or paralleled the epidemic. Seeming natural allies such as groups working on welfare reform, prison issues or

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*Resist Newsletter* is published ten times a year by RESIST, Inc., (617)623-5110. The views expressed in articles, other than editorials, are those of the authors and do not necessarily represent the opinions of the RESIST staff or board.

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Printed on Recycled Paper with Soy Ink



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housing may have historical barriers to linking with HIV/AIDS groups that they may perceive as white-led or elitist. These are real problems that need to be addressed in order to increase our collaboration, and to increase all of our power to bring real change.

CHAMP (Community HIV/AIDS Mobilization for Power) is a new effort viewing this intersection of challenges as an opportunity to strengthen grassroots organizing in the United States to the benefit of movements for HIV/AIDS, social and economic justice, and human rights. We believe that HIV constituencies must participate in local community organizing around issues like housing, prison health care and

immigration policies, and that social justice organizers must confront AIDS in their own communities.

We want to offer regional training and mentorship to a range of activists who want to fight AIDS, and seek to revitalize AIDS prevention activism in a time when the Bush Administration wants to virtually eliminate funding for efforts to teach people how to not get HIV.

The AIDS movement has succeeded when it forged a sense of communities-in-struggle and created an infrastructure for people with AIDS and their allies to learn, strategize, protest, and share lives together. We need to recreate this solidarity in a time of economic downturn and when many people of privilege have left the AIDS

movement.

We must recognize that any movement that loses so many of its leaders through untimely death faces substantial challenges. In the memory of Vito Russo and so many others named and unnamed, we must continue to build the power to end AIDS.

*Julie Davids is a long-time AIDS activist, a core member of ACT UP Philadelphia for 13 years, community organizer for the Health GAP (Global Access Project) Coalition, and is currently navigating the New York City subways as Executive Director of CHAMP (Community HIV/AIDS Mobilization for Power), a national network bridging HIV/AIDS and social/economic justice organizing.*

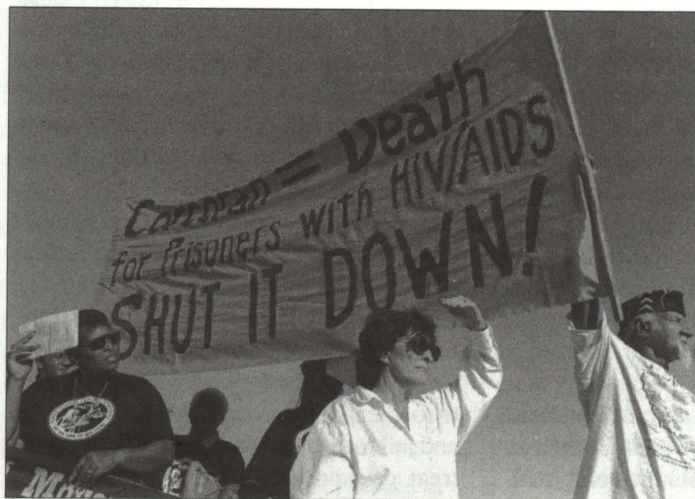
# Prisoners Demand Health Care

## *The Fight for Access and Treatment for Prisoners with HIV and Hepatitis C*

JUDY GREENSPAN

Almost 20 years into the epidemic of HIV/AIDS in prisons and jails, activists are left to wonder: What has really changed? Some incremental improvements have occurred: Prisoners are much more educated about the disease, and there is some semblance of medical care delivery in place at least for HIV. Even so, the amount of HIV infection in prison is at least eight times greater than the outside population and it is estimated that one-quarter of the people living with HIV/AIDS are in prisons or jails. Combined with hepatitis C, HIV has become the most dangerous epidemic in the prisons. While the mass movement demanding care and treatment and a cure for AIDS is on the wane, prisoners are again in an uproar, fighting for their lives and demanding care.

For the past five years, California Prison Focus (a long-time RESIST grantee) has worked to support the fight of prisoners with HIV/AIDS, hepatitis C and other life-threatening illnesses for adequate medical care and treatment. Members of CPF have visited hundreds of prisoners in three California state prisons that house large numbers of people with HIV/AIDS. We have attended national conferences to give presentations about the crisis of HIV/AIDS in prison. We have worked in coalitions to protest the large number of deaths of women



California Prison Focus gathers outside Corcoran Prison in 1998. Photo by Bill Hackwell

prisoners at the Central California Women's Facility in Chowchilla. We have organized community educational forums about the impact of the twin epidemics of HIV and hepatitis C and the continuing struggle of prisoners in California to access care, treatment and basic education about these diseases. During October 2002, we marched and rallied outside of Corcoran, a maximum security prison housing more than 200 men and transgender women with HIV/AIDS. Our lead banner read, "Corcoran is a Death Camp for Prisoners with HIV/AIDS, Shut it down!"

Our most recent event on June 21, 2003—a speak-out entitled "Corcoran

Prison: Medical Center or Death Camp?"—attracted nearly 75 people to the African-American Cultural Complex in San Francisco. Former prisoners gave firsthand accounts about the brutality they experienced in the Security Housing Unit and the poor care they received in the HIV unit at the prison. CPF members who had just returned from visiting

nearly 75 prisoners gave reports about the critical situation there, particularly for prisoners with HIV and renal failure.

### A Short History of HIV/AIDS Activism

The growth of the movement on behalf of prisoners with HIV/AIDS paralleled and drew strength from the early AIDS activist movement. The energy generated on the outside spilled over into the prisons in the late 1980s and early 1990s. While AIDS activists were sitting in and blockading government buildings to demand that new AIDS drugs be approved, prisoners were petitioning and rallying inside, starting peer

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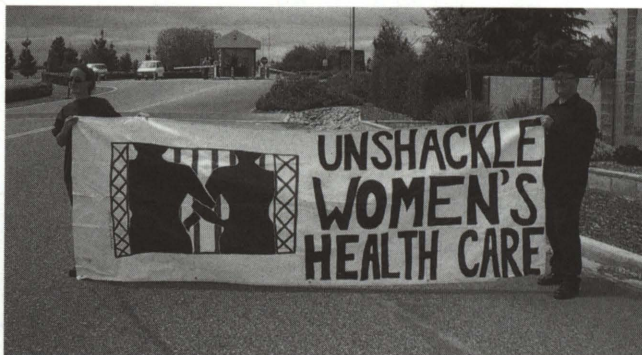
education programs and in some cases, organizing hunger and medication strikes to draw attention to their plight. Many of the prisoners who led that movement have since died, some are political prisoners still serving long terms, and others have been paroled. All too few have been able to find jobs as organizers or peer educators in the community. The AIDS agencies and health care establishment have not given these activist former prisoner the recognition and support they deserve.

During the early days of the epidemic, AIDS and human rights activists in the community, contacted by prisoners inside, were able to reach through the bars and assist this new movement. ACT UP chapters in many cities organized demonstrations outside the gates of prisons and jails. In California, ACT UP even held a raucous sit-in in the offices of the Department of Corrections demanding HIV/AIDS care for prisoners.

The HIV in Prison Committee of California Prison Focus, formed in 1998, has its roots in this AIDS activist movement. By 2000, we added hepatitis C to our name in recognition of the new epidemic. We decided from our inception to monitor and tackle advocacy issues at the two prisons providing the worst medical care for prisoners in California – the Central California Women's Facility (CCWF) and California State Prison – Corcoran. Corcoran is a prison with a long legacy of brutality and torture of prisoners. In the early 1990s, there were more shootings at Corcoran than at all the prisons in the country combined. CCWF, which contains the only "licensed" infirmary for women prisoners, has been consistently investigated since shortly after its doors opened in 1990 for medical neglect and abuse of chronic and seriously ill women prisoners.

## Challenges of Treatment in Prisons

The problems faced by prisoners today with HIV/AIDS and hepatitis C are far more complex than in the early days of the AIDS epidemic. Most prisoners who have any history of injection drug use are infected with hepatitis C. With few exceptions, prison and jail administrators have tended to downplay and ignore the ramifications of the hepatitis C epidemic. Even on the outside, the Centers for Disease Control have minimized the impact of hepatitis C.



Protesters gathered at the Central California Women's Facility (CCWF) to demonstrate their outrage at the lack of medical treatment of women prisoners. Photo courtesy of California Prison Focus

However, a disproportionately high rate of hepatitis C- and HIV-positive individuals reside in prison. By most official and conservative estimates, there are approximately four million people in this country who have hepatitis C. At least one-third of this population is in jail or prison. To further compound a serious problem, it is estimated that at least 65% of the HIV-positive population is co-infected with hepatitis C. Prisoner organizers that we work with put that figure at 85%. Many prisoners are now finding out that they tested positive for hepatitis C more than 10 years ago and no one even told them.

For a "silent epidemic" (a phrase coined by the Centers for Disease Control), there sure are a lot of people dying! In fact, when combined with HIV disease hepatitis C has become one of the most dangerous killers. Co-infected prisoners may have managed to medically stabilize their HIV, but prison and jail medical staffs refuse to adequately treat or monitor hepatitis C, and that's what's killing prisoners.

## Where Have all the Activists Gone?

The most painful part of this crisis is the absence of AIDS activism. Since the mid-90s, the AIDS activist movement has moderated, changed and mostly disappeared. Unfortunately, the emergent nature of the hepatitis epidemic has not fueled a new activist movement. The hepatitis C epidemic, unlike the early HIV one, made a direct hit on the most disenfranchised communities: poor people, predominantly people of color, who were injection drug users. It was almost as if a bomb had exploded in the prisons. These communities were the ones left out of the AIDS activism of long ago.

Prisoners, on the other hand, have risen

to the challenge. As in the early days of the HIV epidemic, prisoners are trying to self-educate about hepatitis C. They are becoming peer educators, writing articles, starting support groups and reaching out to community organizations. Some hepatitis C activists in the community are publishing newsletters directed at prisoners. But a much broader and deeper response is needed to really make an impact.

The fight against HIV and hepatitis C in prison must begin to fundamentally challenge the very foundations of the prison industrial complex. As we advocate for better medical care for seriously ill prisoners, we have to demand an end to the war on people who use drugs. It is that racist war that disproportionately targets drug addicts from Black, Latino and Native American communities that is responsible for the massive incarceration of poor people with HIV and hepatitis C. Our allies are in the prisoners' and human rights movements. We must work with groups fighting to end California's three strikes law and challenging Governor Davis' no parole policy. Finally, we must join in coalition with social justice movements fighting on behalf of poor people and the homeless on the outside because they are casualties of the same war. Fighting for health care for prisoners is not enough in 2003; we must join together to protest and change the entire inhumane system. Only then can we guarantee that our prisons and jails will not be disproportionately filled with poor people of color with high rates of HIV, hepatitis C and other life-threatening illnesses.

*Judy Greenspan is a Board member of California Prison Focus and the chairperson of that organization's HIV/Hepatitis C in Prison Committee. This year, CPF received the Mike Riegle Tribute grant from RESIST, given in memory of the life and work of Boston activist Mike Riegle, a supporter of prisoners' rights, gay and lesbian liberation, and the radical movement for justice. For more information, contact CPF, 2924 16th St #307, San Francisco, CA 94103; [www.prisoners.org](http://www.prisoners.org); [info@prisoners.org](mailto:info@prisoners.org).*



# 97 Miles of Wall, Name by Name

## *Coming to Grips with the Global AIDS Epidemic*

RAYMOND A. SMITH

Throughout the epidemic, views of AIDS have often taken two diametrically opposite perspectives — the highly personalized form of individual stories and memoirs and works of art versus the highly impersonal form of charts and graphs and statistical tables. But are there other ways to attempt to come to grips with the incredible magnitude of the worldwide scope of AIDS, other means of trying to understand the vast numbers involved? Consider the possibility below, one that many Americans can relate to.

In a literal sense, numbers in the millions are beyond human experience or comprehension. But so, too, are numbers even in the tens of thousands. Still, when the number of AIDS deaths in the US hit the 60,000 mark about 15 years ago, a new statistic began to be widely circulated. The epidemic had at that point claimed more Americans than the Vietnam War.

This statistic might seem, on its surface, a bit of a strange—or perhaps strained—comparison. What, after all, did US military casualties in a Southeast Asian civil war really have to do with civilian deaths from an immune deficiency? Conservative pundits were, unsurprisingly, quick to dismiss the figure as meaningless.

But many others understood why this was a powerful comparison. First, the death toll of the sixteen-year-long Vietnam War had been deeply etched into the public consciousness as the collective trauma of a nation. Even more importantly, though, evoking the number of deaths in Vietnam was also one way to help people comprehend the scope of mortality figures — 60,000 individual lives — that had scaled too high for anyone to meaningfully grasp, except perhaps in the purely abstract.

American deaths in Vietnam became etched in stone, literally, with the 1982 dedication of the Vietnam Veterans' Memorial on the National Mall in Washington, DC, which is today the most visited memorial in the country. More than two decades after its dedication, the memorial retains its power.

The monument itself is simple: two sheer 247-foot-long walls of black granite meet-

ing at a right angle. The viewer starts walking alongside a low wall only a few feet off the ground inscribed with a handful of names, then walks step after step after step as the wall grows in height and encompasses more and more names — first hundreds, then thousands, then tens of thousands of deaths.

At the vertex of the two walls, the memorial stretches to more than ten feet high, towering over the viewer. And at that point, the list of names seems to go on forever in

Such are the basic contours of the global HIV/AIDS epidemic at the start of the twenty-first century. Still, 97 miles of wall is far beyond what the eye can take in, and it would take days to visit 1,032 Vietnam Memorials. And with more than five million people worldwide newly infected with HIV each year, some 90 new memorials and nine more miles of wall would have to be built annually.

When our rational ability to comprehend numbers fails us, we have no choice but to

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**[W]hen the number of AIDS deaths in the US hit the 60,000 mark about 15 years ago, . . . the epidemic had at that point claimed more Americans than the Vietnam War.**

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either direction. If the viewer still has not grasped the exact dimensions of 58,209 deaths, their sheer magnitude, at least, becomes inescapable.

Now, consider that in the US the cumulative number of AIDS deaths reported to the Centers for Disease Control and Prevention by the end of 2001 was 462,653—or the equivalent of nearly eight Vietnam memorials, a wall which would stretch on for three-quarters of a mile.

And now, consider that AIDS deaths in the US account for only about four percent of the world's totals. A comparable memorial for global AIDS deaths would consist of over 20 million names and would require 344 Vietnam memorials, about 32 miles of wall.

Yet even the number of AIDS deaths to date pales before United Nations estimates of the number of those now living with HIV/AIDS: 42 million people globally. This figure would require nearly 688 additional Vietnam memorials and about another 64 miles of wall.

Thus, in all, a memorial commemorating all those who have had HIV, living or deceased, would require a total of 1,032 Vietnam memorials, or 97 miles of wall. Reading all the names aloud, at one a second, day and night, would take nearly eight weeks.

turn to metaphors and imagery. Yet what does it tell us if, even in the metaphorical realm, the global AIDS epidemic has become too huge to grasp?

*Raymond A. Smith edits Body Positive magazine. For more information, contact The Body, 250 West 57th Street, New York, NY 10107; [www.thebody.com](http://www.thebody.com).*

### **Global Summary of the HIV/AIDS Epidemic December 2002\***

#### *Number of people living with HIV/AIDS*

Total .....	42 million
Adults .....	38.6 million
Women .....	19.2 million
Children under 15 years ..	3.2 million

#### *People newly infected with HIV in 2002*

Total .....	5 million
Adults .....	4.2 million
Women .....	2 million
Children under 15 years .....	800,000

#### *AIDS deaths in 2002*

Total .....	3.1 million
Adults .....	2.5 million
Women .....	1.2 million
Children under 15 years .....	610,000

\*UNAIDS and World Health Organization AIDS Epidemic Update December 2002; <http://www.unaids.org/worldaidsday/2002>.



# “Free Trade” Costs Lives

## *Access to Medicines, the AIDS crisis, and the FTAA*

ASIA RUSSELL

Recent draft negotiating texts that would create a Free Trade Area of the Americas (FTAA) show this expansive trade agreement will threaten the health of poor people in the Western Hemisphere—thanks to the trade agenda of the most powerful FTAA negotiator, the Bush Administration. In Latin America and the Caribbean, lack of access to affordable medicines for treatable diseases like HIV is already a crisis. But provisions contained in the draft FTAA would dramatically worsen lack of access to medicines, while curtailing or eliminating countries’ recourse to sustainable solutions that would help increase the affordability of desperately needed treatments.

42 million people are already living with HIV worldwide. Ninety-five percent of those people have no access to the medicines that have transformed HIV into a chronic illness in wealthy countries like the US. These people have a death sentence because they are considered too poor to be treated. In this regard, HIV is like many other diseases of poverty—treatment is available, but only to a wealthy minority. As a result, more than 8,500 people with HIV/AIDS die daily—3 million people per year.

In the regions of Latin America and the Caribbean, AIDS is a profound threat to public health—even though these regions are not as heavily impacted as sub-Saharan Africa. Two million people are currently infected in Latin America and the Caribbean. Worldwide, HIV prevalence in the Caribbean is exceeded only by sub-Saharan Africa. Throughout Latin America and the Caribbean the HIV pandemic has eroded development gains, undermined the human rights of infected people and of high-risk communities, and has exacerbated economic crises. Numerous studies have shown that medicines needed to treat other public health problems in the region are likewise priced out of reach.

### **Drug Prices Slashed**

Activists’ efforts to force down the prices of life-extending AIDS medicines, particularly through the introduction of ge-

neric competition, have created pockets of access in some poor countries. In Brazil, national activist pressure has created an AIDS program built on the principle of universal treatment access. This universal access is only possible because of the availability of lower cost generic drugs, and the government’s decision to negotiate price reductions aggressively, using tactics such as the threat of breaking a drug company’s patent monopoly (called “compulsory licensing;” compulsory licensing is permissible under the rules of the WTO).

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## The Bush Administration, working with the pharmaceutical industry lobby, is fighting for tougher patent rights—regardless of the impact on health and access to medicines.

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AIDS-related death rates and hospitalizations in Brazil have plummeted as a result of this internationally lauded program. Brazilians are seeking testing for HIV where they would not have before—because they have hope that if they test positive for HIV, they will have access to treatment and not just a death sentence. Moreover, demand in Brazil for lower-cost medicines has changed the global market; the cost of HIV medicines is more than \$10,000 per person per year in the US compared to about \$300 in many poor countries. Although still too costly for sub-Saharan Africa, this price could bring life saving treatment within reach in the Western Hemisphere.

### **Exit the Doha Declaration, Enter the FTAA**

If the US gets its way, the FTAA would make sustaining or expanding Brazil’s AIDS treatment program nearly impossible. The Bush Administration, working with the American pharmaceutical industry lobby, the most powerful in the world, is fighting for tougher patent rights in the Western Hemisphere—regardless of the impact on health and access to medicines. These patent rights would exceed even the strict rules established by the WTO.

At the last WTO Ministerial in Doha in

2001, developing countries and NGOs won a declaration, called the “Doha Declaration on the TRIPS Agreement and Public Health,” signed by all WTO Members, stating that WTO rules “can and should be interpreted and implemented in a manner supportive of WTO members’ right to protect public health and, in particular, to promote access to medicines for all.” This declaration, opposed by the US and the drug company lobby, gave countries the green light to use WTO rules to promote access to affordable medicines—for HIV or any health problem. The US is now sidestepping the forum of the WTO: in aggressive negotiations of the FTAA and other regional and bilateral agreements, this declaration—a tremendously important political

victory—is never mentioned.

The tougher rules the Bush Administration is fighting for include: 1) extending patent monopolies for drug companies beyond the current twenty year lifespan, 2) drastically limiting the conditions under which countries could do compulsory licensing of medicines, 3) eliminating the ability of FTAA countries to export compulsorily licensed medicines to other countries in need, 4) blocking generic companies’ access to test data needed to do compulsory licensing in a timely and economically viable way, 5) in the FTAA investment chapter, drug companies would have standing to sue governments, potentially to block actions like compulsory licensing, and 6) directing drug regulatory authorities to block approval of a generic version of a drug if there are existing patent claims—increasing the chance that bogus patent claims would prevent generics from coming to market, because drug companies already have normal judicial means through which to enforce valid patent claims.

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# HIV/AIDS Education in Niger

ALINA POTTS

Niamey, Niger is the hot, dry capital of a hot, dry Saharan country in West Africa. While all of Africa's 48 sub-Saharan countries have certain commonalities, Niger differs from the others in at least one significant way: its apparent indifference to HIV/AIDS, one of Africa's most pervasive and destructive adversaries.

Despite recent international attention and steadily climbing infection rates, many Africans living in Niger are largely uninformed about the HIV/AIDS epidemic. As a student intern with the United Nations Fund for Population Activities (UNFPA) in Niamey last year, one of my first projects was to create HIV/AIDS education posters to be displayed on city buses. While my experience in Niger may seem less urgent than HIV/AIDS work in other African countries with higher infection rates, the lessons I would learn about cultural sensitivity, determination, and communication are applicable to HIV/AIDS education in any country, on any continent.

The initial challenge of an educational campaign is to find out what the target audience already knows, or *thinks* they know, about the topic at hand. This was the first task for my fellow intern, Emily, and I. We took to the streets in a country second only to Sierra Leone as the poorest country in the world. (Sierra Leone has suffered a brutal, 11-year-long civil war; Niger has not.)

Knowing that approximately 80% of Niger's traditional, conservative population of 12 million inhabitants are Muslim, we suspected most people would be uncomfortable—if not downright unwilling—to talk about sex, no matter how indirect the reference. Yet we were not prepared for the response we received to what we thought was a fairly straightforward first question: "What is AIDS?"

The first group of Nigerien women I asked looked at me blankly. When I pressed them, one woman asked me if it was a type of grain. Now it was my turn to stare.

While this level of unawareness is certainly not representative of all Nigeriens, its existence is cause for concern. Last year alone, 17,700 Nigeriens died from HIV/AIDS; current estimates put the rate of HIV/AIDS infection among the adult popu-

lation at about 4%. The highest rate of infection occurs in regions that border Nigeria, a predominantly Christian country with an adult infection rate of 5.8% among a population ten times that of Niger.

Since statistics for both Niger and Nigeria rely only on reported cases, actual numbers are believed to be higher. Even so, an infection rate of 4%, while low in respect to other African countries, remains foreboding. As the Peace Corps in Niger reports, Niger's relatively low infection rates put it at the "critical point where prevention though education can halt the spread of the virus." HIV/AIDS is as crucial an issue in Niger as elsewhere.

## Economic and Cultural Challenges

Like other HIV/AIDS activists, I found myself wanting to educate Nigeriens about the disease yet daunted by massive environmental, economic, social, and cultural challenges. The country's arid environmental conditions both worsen and are worsened by a lack of infrastructure in which schools, health clinics, and public media outlets are scarce. Lack of access to TVs, radios, and newspapers hinder the dissemination of information in a nation with a 15.3% literacy rate. Only 9.4% of women are literate, yet HIV/AIDS infection rates are much higher among African women.

Many Nigeriens deem HIV/AIDS to be an issue that does not concern them. For example, when I showed a Nigerien UNFPA co-worker a sketch depicting a map of Niger and its neighboring countries, with the borders of Niger outlined in red, he looked at me squarely and said, "Oh, I see why the borders are red—because HIV/AIDS stops at the borders of Niger and does not enter. We are immune to it." We quickly changed the color scheme of our design.

While Niger's poverty and relative isolation have traditionally served to deter the spread of HIV/AIDS within the country, these same conditions force many Nigerien men to travel to surrounding countries in search of work. These migrant workers, or exodes, may participate in activities that increase their likeliness of contracting HIV/AIDS. If infected, they will pass on the virus to their wives and children upon returning to Niger. In addition, the exode phenomenon explains why HIV/AIDS rates

tend to be higher in border regions.

## Religious and Cultural Challenges

Religious perceptions also fuel Nigeriens' belief that they exist outside of the HIV/AIDS epidemic. Some Nigeriens insist that it is the looser sexual and drug/alcohol mores of their Christian neighbors that lead to higher HIV/AIDS rates in those countries. Regardless of the accuracy of this conviction, it serves as a barrier to HIV/AIDS educators inside Niger who must first convince many Nigeriens that no one is immune to what is in fact a non-discriminating, deadly disease.

The conservative nature of Nigerien society creates a cultural milieu in which sex and sexuality are not openly discussed. Islamic and traditional beliefs limit the availability and effectiveness of HIV/AIDS preventative measures such as sex education, condom use, and abstinence. Girls are married and expected to begin giving birth at a young age, men may take multiple wives, and women generally are not encouraged to use birth control, if they are even aware of it or have access to it. In addition to inadequate healthcare and testing services, those who do find that they are HIV-positive face strong social stigma if they do not keep their status a secret.

HIV/AIDS education in Niger, and countries like it, remains a difficult but essential task. Culturally sensitive messages relating to the prevention of HIV/AIDS need to be accessible to the population. Activists familiar with Western assumptions of sexuality, women's rights, and literacy rates will be challenged by environments such as Niger, but cross-cultural HIV/AIDS education is not a hopeless cause. By consulting with the local population on what messages they think most effective and most appropriate, by designing highly visual campaign materials for the benefit of those who cannot read, and by remaining sensitive to locally held beliefs about sexuality and HIV/AIDS transmission, we can make a difference in what UNAIDS unequivocally calls "Africa's biggest challenge."

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# RESOURCES FOR HIV/AIDS

*Below is a partial list of organizations and resources for those interested in learning more about global HIV/AIDS. Many include links to further resources.*

## **ACT UP New York**

332 Bleecker St. Suite G5, New York, NY 10014; [www.actupny.org](http://www.actupny.org)

Committed to direct action to end the AIDS crisis; website has many useful links.

## **AIDS Library of Philadelphia**

1233 Locust Street, 2nd Floor, Philadelphia, PA 19107; [www.aidslibrary.org](http://www.aidslibrary.org)

Provides information on HIV treatments, nutrition, and referrals to regional and national resources.

## **AIDS Treatment Activist Coalition**

[www.atac-usa.org](http://www.atac-usa.org); [info@atac-usa.org](mailto:info@atac-usa.org)

A national coalition of AIDS activists working together to end the epidemic by advancing research on HIV/AIDS.

## **The Body**

250 West 57th Street, New York, NY 10107; [www.thebody.com](http://www.thebody.com)

Presents a broad range of materials, articles and analyses about HIV/AIDS, quality of life and political initiatives.

## **Gay Men's Health Crisis (GMHC)**

119 West 24th Street, New York, NY 10011; [www.gmhc.org](http://www.gmhc.org)

A volunteer-supported and community-based organization committed to national leadership in the fight against AIDS.

## **Global AIDS Alliance**

1225 Connecticut Ave., NW #401; Washington, DC 20036; [www.globalaidsalliance.org](http://www.globalaidsalliance.org); [info@globalaidsalliance.org](mailto:info@globalaidsalliance.org)

Dedicated to a collaborative, aggressive Campaign to Stop Global AIDS.

## **Health GAP**

511 E. 5th Street, #4, New York, NY 10009; [www.healthgap.org](http://www.healthgap.org)

Dedicated to eliminating barriers to global access to affordable life-sustaining medicines. Health GAP sponsors Global Treatment Action Campaign (GTAC), a network for access to essential medications.

## **International Gay and Lesbian Human Rights Commission**

1375 Sutter Street, Suite 222, San Francisco, CA 94109; [www.iglhrc.org](http://www.iglhrc.org)

Works to secure human rights of all people through advocacy, coalition building, public education, and technical assistance.

## **National AIDS Treatment Advocacy Project (NATAP)**

580 Broadway, Suite 1010; New York, NY 10012; [info@natap.org](mailto:info@natap.org); [www.natap.org](http://www.natap.org)

Works to educate individuals about HIV and Hepatitis C treatments and to advocate on behalf of all people living with HIV/AIDS and HCV.

## **National Minority AIDS Council**

1931 13th Street NW, Washington, DC 20009; [www.nmac.org](http://www.nmac.org)

Dedicated to developing leadership within communities of color to address the challenges of HIV/AIDS.

## **Stopglobalaids.org**

[www.stopglobalaids.org](http://www.stopglobalaids.org)

A website resource containing information about global AIDS activism, including an email list for updates and action alerts.

## **Student Global AIDS Campaign**

c/o Global Justice 22 Putnam Ave., Cambridge, MA 02138; [www.fightglobalaids.org](http://www.fightglobalaids.org)

A US-based network of student and youth organizations committed to the global fight against AIDS.

## **Technical Assistance Clearinghouse**

c/o Bailey House, Inc., 275 Seventh Avenue, 12th Floor; New York, NY 10001; [www.taclearinghouse.org](http://www.taclearinghouse.org)

Provides links to HIV-related information, and gathers resources to support skills-building, individual growth, and community involvement.

## **Treatment Action Group (TAG)**

611 Broadway, Ste. 612; New York, NY 10012; [tagnyc@msn.com](mailto:tagnyc@msn.com); [www.aidsinfonyc.org](http://www.aidsinfonyc.org)

Dedicated solely to advocating for larger and more efficient research efforts, both public and private, towards finding a cure for AIDS.

## **Joint United Nations Programme on HIV/AIDS (UNAIDS)**

<http://www.unaids.org/>

The UNAIDS website discusses the United Nations' response to the AIDS epidemic worldwide. The site displays publications online and gives users a chance to ask questions.

## Join the Resist Pledge Program!

**We'd like you to consider becoming a Resist Pledge. Pledges account for over 30% of our income.**

By becoming a pledge, you help guarantee Resist a fixed and dependable source of income on which we can build our grant-making program. In return, we will send you a monthly pledge letter and reminder along with your newsletter. We will also keep you up-to-date on the groups we have funded and the other work being done at Resist.

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